

# Informing Families

## Building Trust

Fall 2014

A Partnership for Better Communication  
on Developmental Disability Issues in Washington State



### Changes Ahead: *What Do They Mean for YOU?*

#### IFS Waiver, Service Request List and SSP

With the upcoming redesign of the Individual and Family Services (IFS) program—from state-funded to federal waiver—some things are changing in terms of how people waiting for services will be enrolled when there's new funding.

Currently, if your son or daughter has been assessed and found eligible for services, s/he may be on the *wait list* for Individual & Family Services or maybe a *waiver enrollment database* if you've requested a waiver program.

However, due to changes to IFS and the Community First Choice Option (see sidebar), there's a new term for people who are waiting for services.

It's called the *service request list*, and it includes everyone who has been assessed for DDA eligibility and requested a service.

It's an important term to know because that's where DDA will look when funding becomes available as a result of these program changes that will bring in more federal funding.

As many as 5,000 new people will be enrolled in services beginning mid-2015 and beyond.

About 4,000\* of these individuals will be enrolled in the IFS waiver, which is for children and adults who live in the family home. IFS includes services

such as respite, therapies, behavior support, and other interventions.

Contact your local DDA No Paid Services toll-free number (see below), to request an assessment for the IFS waiver, or to confirm that you are on the service request list.

\* 1,000 will be enrolled in the Basic Plus waiver.

#### The SSP Alternative

An option for SSI-eligible clients assessed to need IFS is a cash benefit program called State Supplemental Program (SSP). It's an alternative to IFS that offers flexibility, choice and self-determination with a monthly cash grant equivalent to IFS funding levels.

If your son or daughter qualifies for SSI based on disability and income, SSP may be something worth asking about.

Ed Holen, Executive Director  
WA State DD Council



#### Region 1

Spokane: 800-319-7116  
Yakima: 866-715-3646

#### Region 2

Seattle: 800-974-4428  
Everett: 800-567-5582

#### Region 3

Tacoma: 800-735-6740  
Olympia: 888-707-1202

#### Personal Care

#### and the Community First Choice (CFC)

Our state is in the process of creating a new state Medicaid plan that includes personal care services.

The Community First Choice is a federal program that encourages states to invest in additional community-based care that increases skills and independence.

Because of additional funding through a higher federal match, more service options will be made available.

In addition to personal care, the state is planning to include the following services:

- skills training;
- back-up supports;
- training on hiring providers; assistive devices that replace human assistance; and ,
- community transition services for people returning from nursing homes or institutions to the community.

The state expects to implement the CFC next summer. Right now, it is still in the planning stages and working with stakeholders.

## Making the Most of High School Transition

by Carrie Morehouse, Guest Contributor

**Our son**, Gregory, was born with a rare condition called Zellweger Syndrome. At the time he was diagnosed, the specialists informed us that because of his deafness, blindness, and cognitive delays, he probably would never learn or live in the community. They advised me to just bring him home and love him, but not to expect much.

We took their advice, and Gregory has been abundantly loved! We also ignored their advice and Gregory was always presumed competent with the capacity to learn and grow.

In school, he was offered numerous special programs for students who were deaf-blind, and he amazed us with his abilities.

He was exposed to numerous community-based vocational opportunities and was enrolled in the School to Work program during his last year of school.

The School to Work is a partnership between school, the county, DDA, DVR, and the employment vendor to assist students in being gainfully



employed with supports in place before they leave school.

We engaged in Person Centered Planning and developed a plan to help provide meaningful opportunities for Gregory.

In June 2013, Gregory graduated from his high school transition program with a volunteer position. Six months after graduation, he got his first paid job at Any Time Fitness.

In addition to work and volunteering, we set up a Medicaid Personal Care provider to be with him during the day.

I was well prepared for the day when the bus didn't show up come fall, but it still wasn't enough.

We soon realized that—despite various community activities, volunteering, and work—we didn't set up social activities to build relationships with peers.

Just like his sister, who went off to college and would come home with tales of her great big new life, Gregory needed a great big life that included other people his age, and more than one caregiver at home with him.

I wished we would have worked on that more while he was in school, so that he left with a circle of friends. It was much more difficult to create without the support of an already established/ manufactured group of classmates.

The good news is, Gregory recently moved in to a supported living situation with peers and caregivers supporting vocational *and* recreational activities that keep him busy and connected to others.

Now, when he comes home or we visit, we learn about his great big new life that includes new experiences, new opportunities, and new friends.

### Tips for Transition Planning

A transition plan drives your son/daughter's IEP and successful transition to life as an adult. Consider what instruction, support and services are needed to achieve goals related to:

- ▶ Employment and/or Post Secondary Education
- ▶ Independent Living Skills (e.g., money management, decision-making, shopping, cooking, using the bus)
- ▶ Housing/In-Home Support
- ▶ Social and Recreational Opportunities
- ▶ Health (nutrition, exercise, self-care)
- ▶ Safety (in the home, at school, work, and community)

### IFBT Transition Toolkit

Our Transition Toolkit includes a checklist for IEP goal-setting, a timeline of what to expect and what to do throughout high school transition years, and links to useful resources. Visit [informingfamilies.org](http://informingfamilies.org) to download, print, and share.



## What's Next? Planning for the Future

Creating a Vision

Having a Plan

Building on Strengths

**When** you've got your hands full just trying to get through the day, it can feel overwhelming to think about the future.

Long-term planning is something that's *out there*, in the distant future, when there's time or (more often) when the bus stops coming and that vague tomorrow is today.

The fact is, the school years will end, and the adult service system may or may not meet all your child's needs.

Here are a few ways that families plan for the future:

- ✿ Creating a vision that builds on their loved one's strengths and abilities and includes all areas of life (e.g., employment, housing, supports, social and recreational life, health, safety, finances).
- ✿ Writing (and updating) a Letter of Intent, which provides guidance for care, support and a vision for the future that expresses your hopes and goals.
- ✿ Applying for eligibility to the Developmental Disabilities Administration (DDA) and requesting an assessment for services.
- ✿ Making the most of high school transition to increase employability, learn independent living skills and connect to the community and other resources.
- ✿ Applying for Social Security Income (SSI) at age 18, which opens the door to many Medicaid services, including in-home personal care and health care.
- ✿ Building a social network and natural support while in school.



### Other things to think about:

- ✿ Guardianship or other types of supported decision-making.
- ✿ Establishing a will.
- ✿ Setting up a special needs trust.

Families who plan ahead are glad they did. It may not solve all challenges, but it makes it easier to identify the gaps and lessen the worry.

For more information on these and other topics, visit [informingfamilies.org](http://informingfamilies.org).

### ADDITIONAL RESOURCES

#### Social Security Administration

To apply for, SSI or SSDI:  
[ssa.wa.gov](http://ssa.wa.gov); 1-800-772-1213

#### Developmental Disabilities Administration

In-home, residential, and community-based supports:  
[dshs.wa.gov/ddd](http://dshs.wa.gov/ddd)

#### Washington Lawhelp

Information on guardianship and decision-making alternatives:  
[washingtonlawhelp.org](http://washingtonlawhelp.org)

#### Parent to Parent

19 programs throughout the state provide information, workshops and mentoring:  
[arcwa.org/getsupport](http://arcwa.org/getsupport)

### DD Life Opportunities Trust

The Developmental Disabilities Life Opportunities Trust (aka DD Endowment Trust Fund) is a special needs trust that allows individuals with developmental disabilities or their families to set aside funds for future use without affecting their eligibility for government services and benefits.

Funds can be used for a wide range of life enhancing services and needs that are not provided by government services or benefits. These may include things like assistive equipment or technology, a trip, or instructional classes on painting or swimming. Funds may also be used to pay for tuition or training and other services that assist with employment.

The DDLT provides incentives in the form of state matching funds on fees for the individual trust accounts. DDLT is the only special needs trust backed by Washington State's financial and organizational support.

For more information about the DD Life Opportunities Trust, visit [ddlot.org](http://ddlot.org), or call 888.754.8798.





## Community of Practice: Focusing on Adult Siblings and Older Caregivers

Every life stage comes with its own challenges to finding resources and supports that increase the individual's independence and quality of life.

However, when the family is the main source of support, the challenges become more complex as both the individual and caregiver age. What role will siblings play? What supports, if any, do the parents need, and how does that affect the individual's needs?

Because this is such a crucial life stage to plan and prepare for, Community of Practice is focusing its attention on the special issues and needs of adult siblings and caregivers of individuals age 40 and older.



Visit [www.informingfamilies.org](http://www.informingfamilies.org) and click on the **Community of Practice** tab to find out how you can help our state better understand and respond to the needs of older caregivers and siblings.

### About Community of Practice

Washington was one of five states awarded a grant for Community of Practice to support families across the life course.

The goals of the Community of Practice are:

- to create a model framework for supporting families that addresses the needs of a family member with I/DD across the lifespan and supports states to develop and sustain exemplary family support practices.
- to build capacity within states and the nation to create policies, practices, and systems to better assist and support families that include a member with I/DD across the lifespan.
- to share lessons learned and products to develop, implement and sustain exemplary practices to support families and systems.

Mailing Label